
The Costs of a Pediatric Hospice Program

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The Maternal and Child Health Bureau, Health Resources and Services Administration, Public Health Service, supported this project through grant MCJ-063703.

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Synopsis.....

The recent literature on economic issues of hospice care leaves several questions unanswered.

The most important issue concerns how this type of care can be made financially attractive to patients and families for whom it is a medical option. A major study of a home-based pediatric hospice program permitted a more careful analysis than was previously feasible of the charges for hospice care and how those charges are paid.

Data on provider utilization and duration in the program were obtained retrospectively on 177 patients. Costs of incidental expenditures and indirect costs were obtained prospectively from the families of 27 patients.

A cost model was developed which is general enough to be used by other hospitals that might contemplate establishing a similar hospice program. Our findings are that insurance coverage, especially for publicly funded patients, is likely to be a major impediment for families deciding whether or not to use a hospice program at home.

IN THE LAST DECADE there has been increased interest in providing health services in community settings, away from the high-technology environment of the hospital. Part of this interest stems from attempts to lower the cost of health care services, but equally important is an increased sensitivity to social and psychological attitudes of patients and their families toward aggressive therapy, especially for terminally ill patients. Special interest centers on hospice care for these patients (1). Although few studies have demonstrated definitive differences along either cost or quality dimensions of hospice care, home hospice is increasingly offered as a care option in major urban hospitals.

Children's Hospital Los Angeles (CHLA) initiated a home hospice program in 1980. In this innovative home care model, CHLA acts as a coordinator and manager of care but does not directly deliver home care services. These services are delivered through referrals to existing home health agencies. This model does not require a major startup effort by the hospital; it can be replicated in any local area where home health agencies exist. A project assessing its development and impact on patients and their families has

recently been concluded and some of the results presented elsewhere ("Description and Evaluation of the Pediatric Hospice Demonstration Model, Final Progress Report," by B. Mitchell. Children's Hospital Los Angeles, 1988, unpublished report).

The CHLA project enrolled a wide variety of pediatric patients with a broad spectrum of diagnoses—AIDS, gastrointestinal disease, neonatal anomalies, leukemia, and other forms of cancer. Likewise, patients' families represented various ethnic backgrounds, socioeconomic strata, and family structure, including both dual and single parent families. Insurance coverage varied as well, including public and private coverage, and some families were uninsured. Care by registered nurses; physicians; counselors; social workers; and physical, occupational, and speech therapists was delivered to the patients in their homes.

The program was well received by parents, for the project enrolled 78 percent of medically eligible patients to whom it was offered. The program succeeded in substantially reducing children's need for hospital care while maintaining parent satisfaction ("Description and Evaluation of the Pediatric Hospice Demonstration Model, Final Progress

'In the case of home hospices that care for patients of any age, wages lost by voluntary caregivers must also be considered as an indirect cost. Wages lost by parents of pediatric patients have been estimated to range from 10 to 25 percent of income.'

Report," by B. Mitchell, 1988, and "Five Years' Experience of a Pediatric Hospice Program," by B. Mitchell, J. Landsverk, and S. O. Schweitzer, 1991. Children's Hospital Los Angeles, unpublished reports).

As a relatively new concept involving families with children suffering from catastrophic diseases, there has been little empirical evidence of the cost of this type of program. While the previous findings of the CHLA project deal with the impact of the program on the patients and their families with regard to stress, adjustment, and overall effectiveness, it is necessary that the cost and financial implications be examined as well. In this analysis we are particularly interested in measuring the total cost of the program, including indirect costs, out-of-pocket expenses, and opportunity costs of volunteer services.

To address many questions of policy makers and health care providers, important cost questions need to be raised. In this paper we ask how the costs of the program were generated, what were the various elements of cost, and how large was each one. When these issues are better understood, programs can be developed to help patients and their families choose care options, the programs can better serve patient needs, and reimbursement systems can be developed that will encourage use of services which are desirable from either a social or personal perspective.

Background

Several studies have been conducted evaluating hospice programs. In these studies the definitions of a hospice include freestanding institutions, facilities located within a hospital, home-based programs, or a combination of these. Different factors make each situation unique. All of the programs studied provide care for terminally ill patients, but some provide care for a specialized case mix, such

as cancer, while others offer services to a more general population.

Many structural factors make models noncomparable. Studies examining the economic aspects of adult and pediatric hospice care must be carefully juxtaposed. One major difference in the cost framework lies in the responsibility for payment. Adults 65 years and older rely on Medicare for the most part, while many patients younger than 65 years use private insurance (2). In home-based programs, the cost of lost wages and lost productivity of other family members significantly constrains a family's financial resources, especially for younger families, but these costs do not appear in customary cost accounts.

For the elderly patient, lost wages are generally not incurred directly. Houts and coworkers (3) found that income lost by patients is inversely related to age, with younger patients suffering higher losses. In the case of home hospices, wages lost by voluntary caregivers must also be considered as an indirect cost. Wages lost by parents of pediatric patients have been estimated to range from 10 to 25 percent of income (3-6). Unfortunately, losses caused by a career change or a change from full- to part-time employment are rarely reported. In those studies that include estimates of indirect costs, lost wages constitute a significant fraction of all indirect costs incurred by hospice program participants.

Most studies that assess indirect costs also note the increased travel costs and expenses for the patient's special food and clothing because of fluctuating weight (3-5,7,8). Travel costs vary according to the different types of hospice, from hospital-based to home-based. Most hospice patients require occasional use of hospital care, and so this transportation cost element (for both the patient and family) applies to all hospice settings to a greater or lesser extent. For freestanding and hospital-based programs, additional costs are incurred as family members travel to the hospice more frequently. Lansky and coworkers (5) also found that families living in rural locations incur more out-of-pocket, indirect expenses due to transportation, lodging for families, and special foods than do urban families.

Hospice patients and those patients not in hospice programs incur the same types of direct medical costs: prescription medication, diagnostic procedures, physicians' and nurses' fees, and inpatient and outpatient costs. These are expenses that all terminally ill patients incur, regardless of the site of care (7). Home-based hospice programs,

however, contain some costs, such as costs for linen and bath supplies, and for nonprescription medicine, which would normally be included in hospital charges for the hospitalized patient but become additional costs for the family caring for a child at home.

Amado and coworkers (2) note that 24-hour nursing costs are also unique to the home hospice situation. In addition, expenses to remodel or rearrange part of the home for the patient uniquely affects the home hospice family (4). In an editorial noting the hidden costs of chronic disease, Rosenblum (9) estimates that special expenses for the patient living at home, such as special furnishings, recreational needs, and household assistance, cost several thousand dollars per family per year.

Other studies have directly evaluated the costs of home hospice care compared with hospital-based hospice care. Camey and Burns' study of the nature, demand, and cost of hospice care claims that the total cost of hospital care appears to be considerably higher than that of hospice care because many costs associated with hospice are "hidden," that is, borne by patient and family and are not directly charged to or reimbursed by third-party payors (10).

Though some studies of hospice costs do, in fact, analyze both direct and indirect expenses, volunteers are often treated as cost-free workers, ignoring the opportunity cost of their efforts. Some third-party payors refer to this type of caregiving as philanthropy, and it is therefore rarely reimbursed. According to Camey and Burns (10), costs borne by patients and their families may cause the costs of hospice care to exceed those of hospital care. In fact, in a study by Kane and coworkers (11), the total cost of hospice care was found to be \$2,500 more than that of hospital care.

On the other hand, Birnbaum and Kidder (12) analyzed data from the National Hospice Study, which was mandated by the U.S. Congress to investigate the implications of including hospice services in Medicare. Their study found that average hospital-based care was 41 percent more expensive than average home care costs. They attributed the difference to the fact that hospital-based patients incur more inpatient care costs than do home care patients. Similarly, a study of non-Medicare patients by Narkiewicz (13) found that hospital-based costs were more than home hospice care costs, overall. Narkiewicz also noted that costs incurred 1 month before death are much less expensive for hospice patients than for hospital-based patients. Perhaps this finding demonstrates

Table 1. Direct personnel cost profiles for home care services for 177 patients by episode and type of provider

Cost profile	R.N.	Social worker	Extended care	All providers
<i>Low</i>				
Mean	\$563	\$86	\$1,828	\$2,562
Standard deviation	664	200	9,251	9,255
Median	330	0	0	582
Range	0-3,025	0-1,562	0-85,888	0-87,024
<i>Average</i>				
Mean	783	110	1,911	2,850
Standard deviation	869	257	9,672	9,684
Median	432	0	0	784
Range	0-3,960	0-2,002	0-89,792	0-91,248
<i>High</i>				
Mean	922	139	1,994	3,158
Standard deviation	1,086	324	10,092	10,122
Median	540	0	0	950
Range	0-4,950	0-2,530	0-93,696	0-95,536

that the last month of care for a terminally ill patient becomes far more expensive when the patient is in a hospital setting, and access to expensive intervention is readily available. It is entirely possible, however, that self-selection plays a role in this comparison if patients in a hospital setting had been offered a home care option and rejected it because they preferred to retain access to more aggressive intervention.

Methods

To evaluate the costs of its home hospice care program, the CHLA project divided the total population into two groups of patients. For one, data were collected retrospectively, and for the other, prospectively. This two-stage data collection design is an attempt to overcome difficulties in obtaining information pertaining to the fatal illness of a child. In many circumstances, prospective data collection is desirable because interviewing the participants at the time of program participation reduces memory biases, and conducting the interviews at important points in the family experience may improve accuracy of data reporting. However, an atmosphere of crisis and chaos when a child is dying may make prospective data collection difficult or impossible. Questions concerning cost and lists of expenditures can be perceived as discordant with the human tragedy unfolding.

The cost framework on which this analysis is based is well established (14-17). We first estimate the direct costs of home hospice care. Direct costs

'The cost of nonreimbursed expenses is likely to be a significant factor in determining the overall success of a home-based hospice program. For many families, especially those of low income, this cost might be sufficient to preclude participation in such a program.'

include wages of health care workers, including nurses, social workers, and various therapists. Medication, another direct cost element, includes prescriptions and over-the-counter drugs. Costs of special clothing and supplies that would not have otherwise been purchased are another important cost.

Because indirect costs are less tangible, they are more difficult to measure than costs directly incurred. An important indirect cost for the home hospice setting is lost wages (the opportunity cost) of the caregiver. In some cases these lost wages are earnings foregone by caregivers who actually lost their jobs. But these lost wages can be more subtle, as when leisure is given up. Vacation time taken to be with the sick child or cutting back on hours worked are difficult to identify. Bringing in a friend or neighbor to be with the child also entails an indirect cost. The time of other volunteers must also be considered. Loss of a volunteer's productive time is just as relevant as that of a factory worker's productive time (15). Both are true costs in that they represent something given up in order to produce the care in the home.

Description of Study Population

Total sample. Three hundred patients were identified by CHLA home hospice staff as being medically eligible for the program during the 8-year study period. They all received hospice services from the CHLA program consisting of evaluation and family counseling, although not all of the children who were tentatively registered actually received care at home. Of these 300 children, 236 went home for hospice care during their episode of illness. Of the remainder, 46 died before they were scheduled to leave the hospital, 12 patients' families refused to participate in the program, 4 patients transferred from Children's Hospital to an-

other health care institution, and records of 2 patients could not be located.

Of the 236 children who went home under program auspices, 10 did not actually receive home care: 6 of them went home without the need for skilled care and 4 others died at home before receiving treatment. The study team was able to abstract home care service records for 177 of the 226 patients who went home and received services. For 49 of the 226 patients, portions of the home care records could not be abstracted because they could not be located, or they were unclear and personnel responsible for the records had left the area and could not be found. Characteristics of patients whose home care records could not be abstracted did not differ from those which were abstracted in terms of ethnicity, coming from a one- or two-parent household, or public or private insurance, and there is no reason to suspect that the reason for exclusion from the study sample was related to any of the study variables. The patients were either studied retrospectively or prospectively, depending on the date of program participation.

Retrospective sample. In the period from August 1980 to May 1985, families of 167 patients who received home care from the program made up the retrospective population. The project team successfully located 114 (68 percent) of the people who had been the primary caretakers in the home. The most frequent reason for the inability to contact the others was that they had moved and left no forwarding address or telephone number. Again, the characteristics of those patients' families who were contacted did not differ appreciably from those we were unable to contact. Of the caregivers, 103 of 114 completed telephone interviews for a response rate of 90 percent. These interviews were given in English and Spanish, and they included material on parent satisfaction and coping behavior, as well as on length of the child's episode of care. They did not deal with cost of care.

Prospective sample. The prospective population comprised the 59 patients who went home to receive hospice care between June 1985 and February 1988. Of these patients, 46 (78 percent) agreed to enroll in the prospective substudy, 3 refused to participate, and 10 either returned to the hospital or died before the study could be completed.

The families in the prospective study were asked to keep cost diaries to record their expenditures during the entire duration of the child's illness. Telephone interviews were also administered by the

Table 2. Average weekly incidental expenses based on 105 weekly observations

Type of expense		Number with expense	Mean	Standard deviation	Median	Range
<i>Linens</i>						
Low cost	}	14	\$3	\$11	0	\$0-67
Average cost.....			5	16	0	0-100
High cost.....			6	21	0	0-154
<i>Bath supplies</i>						
Low cost	}	56	4	6	\$1	0-35
Average cost.....			5	7	2	0-45
High cost.....			6	9	2	0-58
<i>Nonprescribed medicines and supplies</i>						
Low cost	}	38	2	4	0	0-20
Average cost.....			3	5	0	0-22
High cost.....			4	4	6	0-25
<i>Special foods</i>						
Low cost	}	54	14	24	1	0-98
Average cost.....			17	28	2	0-118
High cost.....			19	32	2	0-139
<i>Clothing</i>						
Low cost	}	36	9	17	0	0-77
Average cost.....			12	22	0	0-96
High cost.....			15	28	0	0-130
<i>Total</i>						
Low cost	}	89	33	39	16	0-199
Average cost.....			41	50	19	0-244
High cost.....			50	63	23	0-339

project staff at 2 and 6 weeks after program entry, as well as 3 and 6 months after the patient died or was discharged from the program. Complete data were obtained from 27 of the 46 families who had initially agreed to participate. As before, the characteristics of the patients from the prospective population who either refused to participate in the study or whose records were incomplete were not significantly different from those who composed the prospective sample.

The data on provider utilization and duration in the program pertain to all 177 patients for which program records were available. But for costs of incidental expenditures and indirect costs, the data were obtained from the telephone interviews and expenditure diaries of the 27 families in the prospective sample.

Results

Direct provider costs by episode cover services rendered by visiting registered nurses, social workers, and extended-duty (24-hour) nurses. Table 1 reports these costs for all 177 patients in our study population. The costs reported are not actual costs reported for each patient, but were calculated by multiplying actual utilization rates by charges reported by a sample of four home health agencies

used by CHLA in 1988. Three cost profiles were developed to extend the generalizability of the findings. The highest cost profile reflects the highest cost reported by the four providers for each professional category, while the lowest profile is based upon the lowest cost for each caregiver. The average is based upon the mean for all four. These synthetic cost estimates eliminate the effect of inflation because patient data are collected only for quantities of supplies and personnel hours. The dollar value of these items pertains to the date of the analysis, and not the date of the expenditure.

Occasionally brief home visits were provided without charge by CHLA staff. We calculated the appropriate intermittent visit charges of home care visits by the CHLA staff to impute the actual value of these services. The difference was very slight. The mean cost of registered nurse services (as well as the total personnel cost) increased by \$6 per episode, and the median increased by \$23. As the difference was so small, we report all three cost profiles with contributed services as free, as they actually were. The cost profile for the average charges is perhaps the most generally applicable or representative, but the profile based upon particularly high (or low) wage rates will be applicable to those labor market areas with unusually high (or low) health service charges. Our findings show that

Table 3. Average incidental expenses per week for 27 families

Type of expense		Number with expense	Mean	Standard deviation	Median	Range
<i>Linens</i>						
Low cost	}	11	{ \$5 7 8	\$10 14 16	0 0 0	\$0-45 0-60 0-60
Average cost.....						
High cost.....						
<i>Bath supplies</i>						
Low cost	}	20	{ 4 5 7	5 7 8	\$2 3 4	0-21 0-26 0-35
Average cost.....						
High cost.....						
<i>Nonprescribed medicines and supplies</i>						
Low cost	}	19	{ 3 4 5	3 5 6	1 3 3	0-13 0-17 0-23
Average cost.....						
High cost.....						
<i>Special foods</i>						
Low cost	}	19	{ 11 13 14	21 24 26	1 2 2	0-69 0-79 0-92
Average cost.....						
High cost.....						
<i>Clothing</i>						
Low cost	}	17	{ 11 14 18	13 18 24	11 14 170	0-61 0-84 0-113
Average cost.....						
High cost.....						
<i>Total</i>						
Low cost	}	25	{ 33 42 52	31 40 50	19 23 29	0-96 0-122 0-153
Average cost.....						
High cost.....						

Table 4. Average weekly indirect expenses based on 105 weekly observations

Type of expense	Number with expense	Mean	Standard deviation	Median	Range
Total indirect costs	90	\$159	\$195	\$83	\$0-775
Cut back on number of hours worked	42	51	96	0	0-461
Took sick leave or vacation time	4	7	46	0	0-369
Received help from neighbor or family member	45	59	124	0	0-517
Received help from volunteer of American Cancer Society, hospice, and so forth	40	15	28	0	0-138
Hired help	8	14	74	0	0-664
Received help with transportation	44	13	25	0	0-129

Table 5. Average indirect expenses per week for 27 families

Type of expense	Number with expense	Mean	Standard deviation	Median	Range
Total indirect costs	24	\$140	\$158	\$75	\$0-581
Cut back on number of hours worked	14	53	75	15	0-308
Took sick leave or vacation time	2	7	26	0	0-106
Received help from neighbor or family member	15	51	100	14	0-461
Received help from volunteer of American Cancer Society, hospice, and so forth	10	8	16	0	0-58
Hired help	6	9	23	0	0-88
Received help with transportation	15	11	16	3	0-67

total professional costs are approximately 20 percent higher for high wage providers than for low.

Extended care nurse costs are by far the largest of the three categories. The mean total costs range from \$2,562 for the lowest cost profile, to \$3,158 for the highest cost profile. The distribution of these costs is so skewed (to the right) that the median is much lower—less than one-third of the mean. The range shows that for every personnel category some patients did not use the personnel at all, while some used them extensively.

Direct incidental expenses of supplies and related items purchased for the child cared for at home were analyzed next. Weekly incidental, nonmedical purchases associated with caring for their sick child were reported by the prospective substudy families. In a method similar to that for wage costs, average quantities of purchases for linen, bath supplies, nonprescription medicine and supplies, special foods, and clothing were multiplied by high, average, and low prices observed for the Los Angeles area in 1988.

The incidental costs for all 105 weekly observations for the 27 families are shown in table 2. These weekly observations were not strictly independent of one another because they are clustered by family. Table 3 shows the weekly average incidental expenses with the family as the reporting unit. The mean weekly expenditure is \$41 for the average cost profile looking at all the weekly observations, and it is \$42 using the family as the reporting unit. It is apparent that the results are very similar whether one calculates average costs across all weekly observations or by family. Special foods is the largest component of incidental expenses, followed by clothing. Together, these two items constitute some 66 percent of the total.

Loss of family income while caring for the child and the value of services donated by nonprofessional volunteers, neighbors, and relatives are considered indirect costs. The number of wage-earning hours lost to contributed services were reported by the 27 families in the prospective survey. These hours were multiplied by the 1988 average hourly wage for private nonagricultural employment as reported by the Council of Economic Advisors (18). Calculations were reported on the basis of weekly observations with the family as the reporting unit.

With the week as the unit of observation, the total mean indirect expenses covering all categories was \$159 per week (table 4). The wide range (\$0 to \$775) explains the high standard deviation (\$195). Most of the indirect costs (75 percent) was attrib-

Table 6. Average cost profile for home care episodes by type of cost

Cost profile	Type of cost			Total
	Direct, personnel	Direct, incidental	Indirect	
Mean	\$2,850	\$446	\$1,478	\$4,808
Standard deviation ..	9,684	629	2,085	10,601
Median	785	169	559	1,694
Range	0-91,248	6-3,142	20-10,410	78-97,984

uted to "cutting back on number of hours worked" and "receiving help from neighbor or family member." Taking sick leave or vacation time and receiving help from volunteers or hired persons made up the remaining 25 percent. When these indirect expenses were calculated with the family as the reporting unit, the results were similar (table 5). The mean of the total indirect costs was \$140 per week, just \$19 less than with the week as the unit of observation.

The summary of costs per episode are reported in table 6. For this summary we show together the three cost categories: direct personnel, direct incidental, and indirect. The costs per episode are derived by multiplying the cost per week (with the family as the reporting unit), shown previously, by the average duration of episode reported for the entire sample of 177 patients. This duration was 10.57 weeks.

The mean total costs for our families was \$4,808 per case, assuming average direct costs. The standard deviation was again very large, \$10,601. The range was \$78 to \$97,984. Compared with the total, incidental expenses were modest—\$446—but indirect costs were much larger—\$1,478. The largest component of total cost, however, was the direct personnel cost of \$2,850.

Personnel costs are usually covered by third-party payors, either public or private. However these personnel costs only constitute 60 percent of the total cost of care, with incidental and indirect costs together constituting 40 percent of the total. Of the \$1,958 nonpersonnel cost, three-quarters are the indirect costs of foregone earnings, either of the family, friends, or volunteers.

Discussion

The CHLA home hospice program demonstrated that a home-based hospital-directed program using community-based resources can successfully serve many terminally ill children suffering from various

illnesses. Where home care agencies are available, geographic and social barriers to access for home-based terminal care frequently can be overcome. Children can be cared for at home whether or not they seek hospital outpatient or intermittent inpatient care, or whether or not they continue with aggressive therapy. The program also demonstrated that services can be delivered to both single- and two-parent households in widely varying socioeconomic strata.

The design of this home hospice evaluation did not permit a full economic appraisal of home hospice care, and one cannot conclude that this mode is superior to other modes of terminal care in either cost or quality of care dimensions. But we have shown that it is feasible to account properly for cost elements which are often absent from other economic studies and that the effect of these omitted costs can be substantial for patients' families making personal decisions. The cost of non-reimbursed expenses is likely to be a significant factor in determining the overall success of a home-based hospice program. For many families, especially those of low income, this cost might be sufficient to preclude participation in such a program.

Conclusion

Evaluating the cost of a home-based pediatric hospice program illustrates an important conceptual problem. Reductions in formal care are often achieved only by placing a larger burden upon the patient and his or her family. Accounting for the full impact of this shifted burden is crucially important, though difficult. Without it, two errors are made. The first is that one is likely to understate total costs of programs because new costs are less visible than were the old. Secondly, if there is a divergence between social and private costs one would not expect private decision making to reflect society's optimal allocation of resources. In this case society must find a way of reallocating resources to the decision makers to alter incentives. In the context of home hospice care for terminally ill children, the implication is that if home hospice care is in fact superior to other modes of care, third-party coverage will have to be changed to increase the economic efficiency of treatment decisions.

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